Disability Research Unit
School of Sociology and Social Policy
University of Leeds

"Measuring Disablement in Society: Hopes and Reservations"

Colin Barnes

September 1995

"Measuring Disablement in Society: Hopes and Reservations"

Introduction

Until very recently sociological research on 'disability' has centred almost exclusively on sickness related behaviour, individual adaptation, and deviance and normality. As a consequence, the question of measurement has been restricted to a focus on individuals, impairments, and functional limitations (Martin et al., 1988; Williams, 1979). However, the emergence of the 'social model of disability' has reformulated the nature of the problem to be studied. Here, the causes of disability are linked to disabling barriers and social restrictions, rather than to the functional limitations of people with impairments (Abberley, 1987; Davis, 1986; Oliver, 1983; 1990). It may be argued, however, that the social model of disability, although consistent with existing evidence (Barnes, 1991; Zarb, 1995), is based on a set of assumptions which have not been empirically tested.

The 'Measuring Disablement in Society' project, currently being conducted by the Policy Studies Institute (PSI) under the direction of Gerry Zarb, and the Disability Research Unit at the University of Leeds, sets out to address this problem by providing a systematic empirical analysis of the barriers to disabled people's participation in mainstream community life in 1990's Britain. Besides evidence of the physical, social and economic obstacles confronting disabled people, the project will attempt to show how these phenomena might be measured monitored and, eventually, eliminated.

This paper provides a brief overview of this particular piece of research. It is not intended as a fully worked out critical analysis of the project, this would be impossible at this early stage of its development, but rather a basis for discussion at Hull.

The project's alms.

Although initiated in 1994 this research has its roots in the early 1970s when the Union of the Physically Impaired Against Segregation (UPIAS) called for the 'systematic analysis of the organisation of society' to get at the very 'heart of disability' (UPIAS, 1976, 14). Drawing on a small but increasingly influential body of literature on disability research (see for example Oliver, 1987; DHS, 1992; Rioux and Bach, 1994) it sets out to evaluate the main barriers to disabled people' s full participation in key areas of social life.

These include: a/ physical environments: housing, transport and public buildings and amenities; b/ social and political environments: local 'disability' services, and opportunities for and barriers to user involvement in the running of services and; c/ economic environments: employment, social mobility and income distribution. This will involve a combination of national surveys and intensive empirical research in three case study areas in the North and Midlands - Derby, Leicester and Manchester. Information will be collected from a variety of sources to produce appropriate ratings on a range of disabling barriers on both a national and a regional basis.

The primary aim of the research is to produce effective and usable measures with which to monitor policies and initiatives designed to promote equal opportunities for disabled people. Disabled people and their organisations, local authorities, and other relevant groups will be fully involved at each stage of the project. Through continuous consultation and information exchange with all the relevant parties we hope that the research will identify which disabling barriers are the most significant and how they might be defined and measured.

Methodology.

i. Phase One

The research has three main phases. Phase One, now in progress, involves data collection from a variety of secondary sources and consultation with a range of disability organisations, government departments, and other agencies involved in policies and services for disabled people. The primary reason for this is to identify what is generally perceived as the main obstacles to disabled people's full participation in community life, and to explore ways in which these might be measured through operational research.

Using a combination of published and unpublished secondary data sources, statistical ratings are being constructed to assess their effectiveness as indicators of levels of inclusions and exclusions. For example, information on the number of accessible houses in different local authority areas is being collected and comparisons produced. Also, we hope to produce comparative ratings on the scale and level of services for disabled people in different locations, with a particular emphasis on services promoting 'independent living'. Additionally, data on regional employment rates are being collected which take account of local labour market conditions. The aim of which is to try and assess the relative levels of inclusion or otherwise in the workforce in different parts of the country.

These ratings will then be compared to the various performance Indicators which local authorities are required to publish under the Citizen's Charter, Parent's Charter and similar documents. This will raise the question of how well these Indicators reflect the levels of inclusion and exclusion of disabled people, and whether alternative measures might be more appropriate.

This information will be supplemented by data from national postal surveys of local authorities and other relevant organisations. The first - a survey of regional transport authorities - is now under way. This will help to provide an indication of how much of the public transport system is accessible to different groups of disabled people in different parts of the country. Other planned national surveys will collect information on policies on access; services for different groups of disabled people; the involvement of disabled people in local planning; support for and partnership with representative disability organisations; and the employment of disabled people.

Because most of this data is collected for different reasons the value of any statistical ratings produced will be only limited. Similarly the information from postal surveys will also need to be refined and tested through intensive fieldwork. Furthermore, any issues raised during consultation with disabled people's organisations will need to be examined. We hope that this can be achieved during the second stage of the project due to begin in early 1996.

ii. Phase Two

Phase two will entail extensive empirical research in three designated areas. Following preliminary discussions with the relevant authorities and organisations, it is almost certain that the relevant areas will be Derby, Leicester and Manchester. It will involve four areas of activity. These will include: research on local policies and practices; the construction and testing of methods for assessing their effectiveness in terms of the inclusion/exclusion of disabled people; a survey of local disabled people; and an access audit of the local physical environment.

The specific details of the research on local policies and practices will be dependent on the findings of Phase One of the project. However, it is likely to include interviews with key people in relevant local authority departments and local disability organisations. We hope to discuss local policy developments, priorities for research and monitoring (including local priorities and key issues identified in Phase One); and explore how to implement other planned elements of the research including the survey of local disabled people and access audit.

The study will gather data from local authorities' staff on local 'disability' services.   This is likely to include general information on local authority spending on disability services, house adaptations, access schemes; employment policies and numbers of disabled employees; disability equality/awareness training; number of organisations of and for disabled people in the local authority area and details of policies and practices for the involvement of disability organisations in consultation and planning.

Specific information will be needed on more technical matters. This will include details of the number of houses (local authority and housing association) meeting wheelchair or mobility standards, housing waiting lists, and local policies for the allocation of housing to disabled people. Information on the implementation of Part M building regulations, the number of prosecutions, warnings and so on for non-compliance, policy guidance and procedures for monitoring access standards in private sector housing developments will also be required. Additionally, data on specific measures to improve access in public amenities - dropped kerbs, lighting and communications systems.- transport facilities for disabled people, and the number and location of parking places for Orange Badge holders will be collected.

Other information needs include details of services for disabled people (including the availability of independent living and self operated personal assistance schemes and direct indirect payments), numbers of users, and or service hours provided, budgets and mechanisms for monitoring services.

Besides assistance collecting information about the operation of local policies and services we intend to involve both the local authority and local disability organisations in the design of the empirical research. This will relate to the design of survey questionnaires, sampling for the survey of local disabled people, and the access audit. While the main objective is to develop measures which can be used elsewhere, the close involvement of local people offers the opportunity to shape the research according to local interests. In turn, this will ensure that the research outcomes will be of practical use for the further development of local policies

Again, the precise detail of this part of the project will be partly determined through consultation and findings from earlier stages of the project. There are, however, certain issues which we have already identified as priorities for further investigation.

We are especially interested in the extent to which disabled people are involved in, and able to influence, local planning, notably with reference to housing and access, transport and social services, To collect this information, we hope to interview representatives from relevant local authority departments, other agencies, and local disabled people. We are particularly interested in the extent to which disabled people feel able to have any say in decisions effecting their daily lives. For disabled participants, it is likely that this aspect of the research will be incorporated into the general survey described below. However as part of this process, we hope to develop practical tools for assessing the effectiveness of local policies designed to extend equal opportunities and rights for disabled people with reference to housing, 'community care', and employment. This will include mechanisms for measuring and assessing the degree of direct and indirect discrimination encountered by particular sections of the disabled population; examples include, older disabled people, people facing communication barriers, and disabled members of minority ethnic and racial groups.

It is hoped that the interview survey of local disabled people will provide a means of developing and testing additional ratings based on their lived experience. This will help to ensure that any measures we produce will be sensitive to the experiences generated by disabled people themselves, and that they incorporate and address their main priorities.

The survey in each local authority area will comprise semi-structured interviews with a representative sample of 75 to a 100 disabled people with physical and sensory impairments. The sample will be stratified accordingly to reflect the demographic profile - age, gender and ethnic origin - of the local population of disabled people. The sample will be drawn from membership of local organisations of disabled people and users of voluntary and statutory services. Prospective participants will be sent a standard letter and appropriate questionnaire, to obtain basic background details, plus a reply form and pre-paid reply envelope. If they indicate a willingness to participate they will be contacted accordingly and the interviews arranged at their convenience.

Whilst it is impossible to stipulate at this stage the content of the interviews, they are likely to include items on access and the physical environment: problems, improvements, and the need for further improvement. This information will be used later for the design of the local access audits discussed below. Other questions will focus on the use of local services, satisfaction ratings, adequacy of services in terms of meeting user 5 self defined needs, access to disability related information, and perceptions of the degree to which people are able to contribute to and influence the development of local authority policies on issues affecting their daily lives.

Examples include, town planning and community care plans. The access audits will help develop comprehensive ratings for measuring the accessibility of physical environments that can be applied to public buildings and amenities such as council buildings, bus and railway stations, shopping centres and recreational facilities. The fieldwork will be based on established measures like those produced by RADAR (The Royal Association for Disablement and Rehabilitation) and CAE (The Centre for Accessible Environments). These will be modified in accordance with issues and points raised during consultation, and by the survey of local disabled people. The access audits will pay particular attention to the access needs of people with sensory impairments, mobility related impairments who are not wheelchair users, and wheelchair users. We hope to survey a minimum of 15 sites in each location. To validate findings, the audits will be conducted be researchers and volunteers from local disability organisations.

iii.   Phase Three

The final stage of the project will carry out national surveys of local authorities and other relevant organisations using some of the measures developed and tested in the three case study areas. For example, the empirical analysis of disabled people's involvement in local planning procedures should enable us to construct tools for measuring these practices in other areas. Similarly, the case studies will identify key questions which will cast light on other aspects of inclusion and exclusion such as the effectiveness of local policies on access; and the existence of practical programmes aimed at extending rights and opportunities for local disabled people.

The overall aim of the project is to demonstrate practical ways of measuring the extent of inclusion and exclusion of disabled people in the economic, political and social lives of their communities. The outputs from the project will be useful to disabled people and their organisations in highlighting the barriers to their full and equal participation in society, and monitoring the impact of measures aimed at removing those barriers. Moreover, since there are few established ways of measuring disabling barriers, the indicators developed by this research will be particularly useful to local authorities and other agencies with responsibility for promoting equality for disabled people.

In terms of dissemination, besides the usual research reports, articles, conference papers and so on, all participant organisations will receive a detailed local report of findings and issues arising from the research. We hope that this will ensure that the information produced is of maximum practical benefit to the development of local policy and practice.

In addition, Summaries of the findings will also be produced and circulated to the national network of disabled people's organisations via the BCODP (British Council of Organisations of Disabled People) Research Unit which is also situated in the Disability Research Unit at the University of Leeds.

Conclusion

This is an ambitious project which I believe will further establish disability as a legitimate area of study within mainstream sociology. The methodological issues raised by this research alone are particularly relevant to sociologists interested primarily in research methodology. On a personal level, the project fulfils all my own criteria for doing disability research. It takes as its starting point the 'social model of disability' - it is about researching the oppression of disabled people; disabled people will be fully involved throughout its duration; and, hopefully, the results will contribute to the empowerment of the disabled population as a whole.

This is despite the project's obvious limitations. The most Important being that the needs of large sections of the disabled population will not be fully addressed. This is particularly the case for those living outside cities and people with learning difficulties and mental health system survivors. The empirical research focuses on the urban rather than the rural environments, and the project is mainly concerned with the needs of people with physical and sensory impairments. This brings me to another equally important point, although certain aspects of the obstacles to disabled people's participation may be amenable to measurement, physical access, for example, there are other issues which are not; namely, prejudice. In employment, for example, despite well drafted and publicised equal opportunities policies in many cases the employment of disabled workers is, in the final analysis, dependent upon the judgement and attitudes of one or two key individuals. Prejudice and attitudes are notoriously difficult to measure. Clearly, these and other issues will be considered as far as possible as the research progresses. Hopefully, the discussions at Hull may help in this regard.

References

ABBERLEY, P. (1987) **'The Concept of Oppression and the Development of a Social Theory of Disability'** in Disability, Handicap and Society, 2, 1, pp.5 - 21.

BARNES, C. (1991) **Disabled People in Britain and Discrimination: A Case for Anti Discrimination Legislation** London, Hurst and Co.

DAVIS, K. (1986) **Developing Our Own Definitions: Draft for Discussion** London, British Council of Organisations of Disabled People

DHS. (1992) Disability, **Handicap and Society: Special Issue on Researching Disability** Vol.9, No.2.;

MARTIN, J., MELTZER, H. and ELLIOT, D. (1988) **The Prevalence of Disability Among Adults** London, HMSO.

OLIVER, M. (1983) **Social Work and Disabled People** Tavistock, Macmillan.

OLIVER, M. (1987) **'Redefining Disability: Some Implications for Research'** in Research, Policy and Planning, No.5, pp.9-13.

OLIVER, M (1990) **The Politics of Disablement** Tavistock, Macmillan.

RIOUX, M. and BACH, M. (1994) **Disability is Not Measles** Toronto, University of York, L'institute, Roeher.

WILLIAMS, R. G. A. (1979) Theories and Measurement in Disability in **Epidemiology and Community Health** Vol.33, pp~3247.

UPIAS (1976) **Fundamental Principles of Disability** London, Union of the Physically Impaired Against Segregation.

ZARB, G. (1995) **Removing Disabling Barriers** London, Policy Studies Institute.